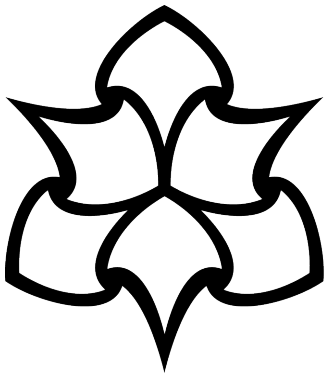

Book 3: Palliative care within mental health: ethical practice

Chapter 21: End-of-Life Care: alcohol and other drugs

Professor Sarah Galvani
Professor of Adult Social Care
Manchester Metropolitan University
Brooks Building
53 Bonsall Street
Manchester
M15 6GX
Tel: 0161 274 2579
Mob: 07775 680418
Email: s.galvani@mmu.ac.uk

Dr. Gemma Anne Yarwood
Strategic Partnership Lead (Manchester Metropolitan University & Pennine Care Foundation Trust)
Senior Lecturer
Department of Social Care & Social Work
Manchester Metropolitan University
Birley Building
Bonsall Street
Manchester
M15 6GX
Tel: 0161 247 2509
Mob: 07968 622762
Email: g.yarwood@mmu.ac.uk

Word Count: 8075

<ch number> Chapter 21

<ch title> End-of-Life Care: alcohol and other drugs

<authors> Professor Sarah Galvani and Dr. Gemma Anne Yarwood

<A>Introduction

This chapter bases its discussion of ethics around an innovative research project exploring end-of-life care for people with a history of problematic alcohol or other drug use (hereafter, substance use). The project was led by researchers at Manchester Metropolitan University in partnership with professionals from three hospices, three substance use agencies and one community-based organisation in England. The research set out to explore whether people experiencing problematic substance use, and their family members, friends and carers (FMFC), faced health inequalities in accessing end-of-life care or substance use support, in part through documenting their experience of services. Further, it sought the experiences of the professionals involved in delivering services to this group of people including key professionals from different disciplinary areas around the UK, for example, social workers, hepatologists, community nurses, GPs.

During the development of the project, the design of the research tools, and the collection and analysis of data, there were a number of important and highly sensitive ethical issues to address. Most of these had been identified by the research team ahead of time but others, as in practice, emerged as the project progressed. Throughout the project, practice partners and members of the research team debated and discussed ethical questions as they emerged. This was vital to ensuring our research practice was informed and as sensitive as possible to the needs of the people receiving services and the professionals delivering them.

This chapter will present six ethical questions organised in a chronological order and broadly located around the following core questions:

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- should we do the research if there is the potential for causing distress?
- how do we do it ethically - with sensitivity towards people who experience problematic substance use and end of life care needs, and their family members, friends and carers?
- what are some of the key ethical dilemmas professionals face when working with these combined issues?

<end bullet>

In social and health care practice, there is a parallel process of questioning and reflection about ethical practice, sensitive and non-judgemental intervention, and concern for the impact on people who use services.

Of the six ethical challenges presented – four were raised by the research process, and two were raised by participants. In starting out, we thought these challenges would split into two clear camps: research- or practice-based. In most cases, we found that the reality of research which is practice focussed means the two are inextricably linked. Challenges in one have clear parallels in the other. In addition, we found ourselves debating the blurred margins between what was a practice or research challenge and what was an ethical challenge. In navigating these margins, we asked ourselves ‘what would be unethical research or practice in this situation’? Where relevant we have illustrated the discussion with pseudonymised quotations of the people we spoke to.

We begin by summarising the key concepts used throughout the chapter before offering some background evidence to contextualise the research and chapter. A summative policy context is then provided before moving on to discuss the selected ethical challenges, our reflections on them and the implications for practice. The chapter concludes with a summary of key points and resources for further learning.

<W>Box 21.1 – Learning the language

Problematic substance use – this refers to the use of substances that has become problematic in some way for the person using them. This could be problems relating to physical or mental health, finances, relationships, crime, and employment. This terminology is preferred to alternatives that have become increasingly stigmatising and labelling, such as addiction or addict. Moreover, substance 'abuse' or 'misuse' are often little understood and taken to mean any use – problematic or not – of any type of illicit drug use, often excluding alcohol. 'Problematic substance use' terminology stems more from a social and non-judgemental model and lends itself to asking, 'what problems is it causing' as a practical next step in the conversation.

End-of-life – the end of someone's life can be sudden or spread out over many years depending on a range of factors including diagnosis, lifestyle factors, treatment access and availability. This makes clear definitions difficult. The National Institute for Care Excellence (NICE) define it as:

<quote>

'people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions' (NICE 2017, online).

<end quote>

However, the end of life could mean years, months, weeks or days of remaining life.

<end Box 21.1>

<A>What is the problem?

Life limiting conditions including liver cirrhosis, chronic obstructive pulmonary disease, various forms of cancer, heart disease, and dementia are linked to the problematic use of substances and alcohol (Institute of Alcohol Studies 2013). There are no figures on how many people are living with chronic or terminal ill-health and using substances problematically; nor is their demographic profile known. For some people, their problematic substance use can lead directly to their chronic or terminal ill-health, while for others their substance use may co-exist with their ill-health.

While problematic substance use can seriously damage the health of younger people (Effiong et al. 2012), older people are disproportionately affected given the increased likelihood of other pre-existing health conditions (Department of Health 2008; Rao 2013). Evidence shows an increase in the rate of alcohol-related hospital admissions among older people (Wadd and Popadopoulos 2014) and an increase in illicit drug use among older age groups (Beynon, Stimson & Lawson 2010). This is predicted to grow further, placing significant demand on end-of-life and palliative care services (Dixon et al. 2015).

While some people may change their substance use behaviour as they age or become ill, not everyone does (Holdsworth et al. 2014). While there is much written about the importance of palliative and end-of-life care services being ready to meet the needs of our ageing population, little is known about how these services support people experiencing substance

problems and if, or how, they do so at present. At the core of service provision sit the professionals who deliver it. It is their attitudes and engagement with these co-existing issues that are likely to be key to the engagement and care of individuals and their family members. It is vital not to forget the needs of family members in this context (*See* Chapter 16). There can be considerable negative impact on family members, friends and carers from an individual's problematic substance use alone (Orford et al. 2010). This is likely to be exacerbated as their relative nears the end-of-life (Valentine and Templeton 2013).

To summarise, the number of people with problematic substance use histories is likely to increase among our ageing population. This is in addition to the increasing complexity of health conditions that longevity and older age bring. Specialist services need to be prepared to address the ethical and practice challenges posed by a substance using population at the end-of-life and policy initiatives need to be ready for the challenge.

<A>Policy environment

From an ecological theoretical standpoint, understanding the impact of wider socio-political environment in which we exist as individuals, organisations, communities and society is paramount (Bronfenbrenner 1977, 1986). Among the influences that affect change in this environment are changes in Government. The impact of such changes are felt at national and local policy levels and ultimately by front line services and the people who use them. At the time of this research project there were four key policy considerations that are important to understand in contextualising the research, its ethical challenges, and its practice implications:

1 A focus on health inequalities including in end-of-life care.

In England, the Government set out clear goals to reduce the health inequalities resulting from…

<quote>

'social, geographical, biological or other factors' (NICE 2012a online). [It states there is a need to address health inequalities] 'to reduce the difference in mortality and morbidity rates between rich and poor and to increase the quality of life and sense of wellbeing of the whole local community' (NICE 2012a online).

<end quote>

Pre-existing government policy on palliative and end-of-life care seeks to offer all people approaching end-of-life a needs assessment and high-quality care (Department of Health 2008) but it is unclear to what extent this applies to people experiencing problematic substance use who are often marginalised in health and social care services (Room 2004; Schiffer and Shatz 2008).

2 Austerity measures and their impact on service commissioning.

The British Government's economic policy under its Coalition Government pledged to reduce the UK's deficit bill (H.M. Treasury and Osborne 2013). The pledge continued with successive annual budgets (H.M. Treasury and Osborne 2015; H.M. Treasury 2017) in which the Government announced further austerity measures or funding cuts . As a result, there were direct consequences to regional government budgets and, in turn, to health and social care commissioning. In the substance use field there was a rapid recommissioning of services which saw the closure and reduction of a number of services, or transitions to new providers (Public Health England, 2014). This context of

austerity, job losses, system change and shrinking resources was the operational context in which this project was conducted.

3 Concern about an ageing demographic and its impact on service provision.

By 2036, the percentage of the population over 65-years-old will have increased from its current 18% to 23.9% (Office for National Statistics (ONS) 2017). Simultaneously, in the four nations of the UK, people in the age group, 65-74 years, are either increasing their alcohol intake compared to other age groups or drinking above daily guidelines (Wadd et al. 2017). Thus, the emerging picture is one of an increasing number of older people requiring health and social care services, a lack of funding to support those services (Age UK 2017) and a trend of increasing alcohol and other drug use among older age groups.

4 A 'recovery' focussed substance use commissioning landscape.

The 2017 Drug Strategy adopted the language of 'recovery', promoting an emphasis on full recovery from 'dependence' on substances, with peer-led, community and family support (H. M. Government 2017). For people experiencing problematic substance use and end of life care needs, such notions of, and mechanisms to, recovery are not appropriate. This raises professional challenges for those delivering such care and support as they need to step out of the dominant policy discourse within which their wider service provision is framed and find a way to defend and promote their work while providing complex level of care. Moreover, it potentially alienates a group of people for whom full recovery is not an option because of their health status.

<end number>

Thus, the current policy context highlights the importance of identifying and addressing health inequalities while at the same time expects solutions to be delivered within existing or shrinking resources. At times of economic recession and budgetary restraint it is often the services or the needs of people in minority or marginalised groups that are lost in order to deliver to the majority or mainstream. This political context raised the first ethical consideration:

<Z>Ethical Challenge 21.1

<B>Question: Is it ethical to conduct research if there is doubt about whether or not the findings and recommendations will be operationalised?

<B>Reflections: Our reflections and discussions with our practice partners provided the solution. The co-existing issues of substance use and end-of-life care were presenting concerns and problems operationally and the partner organisations were keen to have some research to underpin service development. However, whatever the funding and other resource limitations in relation to implementing larger scale change, professional attitudes and genuine engagement with people remain the key to good service delivery. Testimony from individuals, families, friends and carers who use end-of-life and substance use services was needed to evidence their experiences, identify their support needs, and inform future policy and practice models that were responsive to their needs. This research set out to collect such testimony and to disseminate it as widely as possible to try to positively influence operational issues for the benefit of people using services and those delivering them. While operational change at service level is beyond the control of the research team, the commitment to translating project findings to operational practice and disseminating that guidance widely is not.

<B>Implications for practice: The parallel for practice would be conducting an assessment of the individual's needs knowing that nothing could be provided. Arguably, it is unethical practice if an individual in a position of power asks for information that is personal and sensitive, knowing that the information will be recorded but not actioned in any way. Operational change can take place at individual and organisational levels and professionals can control the former while advocating for the latter if required. What is important is having clarity from the start about what the information requested is for, who will see it, and what will be done with it. The decision of whether, what and how much to disclose is then with the individual concerned.
<end EC 21.1>

Having resolved the first challenge in collaboration with our practice and community partners, there was another ethical question right at the heart of the research project:

<Z>Ethical challenge 21.2
<B>Question. To what extent is it ethical to discuss sensitive issues relating to people's current or previous problematic substance use with a person who is at (or near) the end-of-life?

<B>Reflections: Underpinning this question are two ethical concerns. The first relates to the general concern about invading people's privacy, and the limited time they have left, when they are so near to the end-of-life; the second, relates specifically to the discussion of problematic substance use, and the stigma and sensitivities that accompany substance use. There were concerns that in asking people about it they may be embarrassed or

uncomfortable or defensive. In other words, as a team of researchers and practitioners, we questioned whether it was ethical to engage in discussions with individuals which we anticipated would likely prompt a range of negative emotions - something they could do without in the final period of their lives. However, one of the main aims of the project was to explore whether people experiencing problematic substance use received the best possible care at the end-of-life. Without talking to people about their experience this was not going to be possible. To omit people with experience from the project because of:

<bullet>

- the potential sensitivities of the subject matter and
- their health status

without providing them with a choice felt assumptive and patronising.

<end bullet>

The primary consideration here was about people's choice to participate and whether or not they had capacity to do so. If they agreed to participate, it was the researchers' responsibility to ensure it was done in a way that was sensitive to their social and health care needs, for example, not taking too much time.

To give people a voice about their experiences and care is not just about informing future service development, it would also allow people to be heard in a way they may not have been heard before. Quite often people reported being dismissed or overlooked in health and social care settings because of their substance use. One of the people we spoke to about her experience was Barbara, (57). Her experience involved a range of health professionals who had failed to ask her questions relevant to her treatment.

<C> Barbara 21.1

[The gastroenterologist] treated me as another person who just drank. He didn't know my background, he didn't know I was abused mentally and physically, he didn't know anything, but he just, he just saw a six-stone alcoholic and that is all he could see. There was no, no delving into my past. And his words were in 2010, when I left, He said "we'll discharge you now" he said, "but no doubt we'll see you again in the future". Now how un-motivational is that?

<end Barbara 21.1>

In this scenario Barbara wanted to be asked about her substance use and reasons for it, and to have conversations about her health. She was not aware of what the diagnosis meant nor what she had to do to improve her chances:

<C>Barbara 21.2

… I'd been told I'd got cirrhosis[1], I didn't really know much about cirrhosis. The doctors told me "you've got ascites[2]". I thought, "what the hell is ascites?" I couldn't spell it never mind know it at the time. And I was discharged from the hospital after two weeks of being drained … And within four weeks I was back in again because I was given no knowledge of diet, such as low salt, you can't do this, you can't do that, I didn't pick up a drink but my stomach grew and grew and I thought "hang on a minute what's going on here?" So I was back in again for another four weeks, where I had another two drains and I said to them "Look, I'm not leaving this hospital until somebody tells me what is going on".

[1] Cirrhosis is 'scarring of the liver caused by long-term liver damage. …Cirrhosis can eventually lead to liver failure…which can be fatal' (NHS 2017, online)

[2] Ascites is a 'build up of fluid in [the] abdomen (tummy) and around the intestines' (NHS 2017, online)

<end Barbara 21.2>

People experiencing alcohol and other drug problems, and those who support them or work with them, have long reported stigmatising and dismissive attitudes towards them in relation to their health care needs. Throughout this project we heard many more examples of poor care than good care, often at primary and acute care facilities.

<B>Implications for practice: Understanding the importance of having conversations with people about their health and substance use, without passing judgement, is fundamental to delivering care effectively. Indeed, it is arguably unethical not to ask about such co-existing issues when it could have such a bearing on their treatment, comfort and care. These conversations may need repeating, particularly if there is cognitive impairment related to the person's substance use or health condition, but people need the information if they are to make informed choices. Professionals need to develop an awareness of the impact of their language. Medical terminology like that used with Barbara (above) may need clear explanation accompanied by checking the person's understanding of their condition, diagnosis or prognosis. However, this is not just about providing information, rather it is about being prepared to have a conversation about substance use and end-of-life care of which that information is part. Even if the person's choice is to continue their problematic substance use, a caring, non-judgemental discussion needs to be had about what the implications are for their health, well-being and death, and how they would like to be supported in the time they have remaining.

<end EC 21.2>

Having decided that it was ethical to conduct the research, the next related ethical challenge was how to go about it:

<Z>Ethical challenge 21.3

<B>Question. What would be the most ethical and sensitive way of collecting data from people experiencing problematic substance use who may only have weeks to live and whose health and capacity to participate might change daily?

<B>Reflections: First, qualitative data collection was felt to be the most appropriate way to collect data on people's experience but the type of data collection, for example, semi-structured interviews, focus groups, digital stories, was open for discussion. Through our consultation with the hospice, substance use and community partners, it became clear that there was no single approach to data collection that would suit everyone due to the varying needs and preferences of the people with experience. We had to consider that people at the end-of -life had limited time and their ill-health probably meant limited energy and attention. Therefore, we needed to be flexible about how we collected the data while staying focussed in order not to waste, or take up, too much of the person's time. We were aware that going back to people for further information or to verify our findings was not going to be an option for some people, so a clear focus for data collection while giving people a voice was needed. This was resolved through offering a menu of data collection options from which the person could choose, or circumstances might dictate. This became known as P.E.M. or Person-centred Evolving Method, a process that began with initial tentative conversations about the research and possible participation and moved towards options of data collection combined with flexibility about when to do them, for how long and who could be present.

Second, the language we used to explain what the research was about also required careful consideration. Being transparent about 'end-of-life' research would be more appropriate with

people accessed through the hospice services, but they may be resistant to discussing their substance use, particularly if their previous experience of discussing it with care services had been negative and judgemental. Similarly, people in substance use services may be able to talk freely about their alcohol or other drug consumption but not consider themselves at the end-of-life, even though they may be very unwell. It was not our place to inform or remind someone, however inadvertently, that they were at the end-of-life. To avoid this, we drew on the expertise of our practice partners and members of the research team who helped us understand the language we should use.

<B>Implications for practice: There are clear parallels between collection of data in a research context and the collection of information for ongoing health and social care assessments in end-of-life or substance use services. Both are often driven by procedural models of questioning (Smale, Tuson & Statham 2000) with professionals required to complete at least one form as part of the process. Such models often drive the order and type of questions posed and the type of language used. Further, there is usually a set timeframe within which the information needs to be gathered and reported. As with the research data collection, there is often a range of ways to collect information from people about their needs which avoid a question and answer model and are far more person-centred. People experiencing problematic substance use often have fluctuating capacity depending on levels of intoxication and people with life limiting ill-health will also have peaks and troughs in their health status and ability to function. A combination of the two therefore, can result in uncertain behaviour and capacity. Therefore, professionals need to adopt a flexible approach to assessment and care grounded in an understanding of the potential impact of substance use on the person's capacity to participate, in addition to their other health needs.
<end EC 21.3>

In addition to the needs of individuals with problematic substance use who were receiving end-of-life care, an important strand of the project was talking to family members, friends and carers (FMFC) about their experiences of, and perspectives on, services. In preparing for collecting new data from FMFCs, the research used an approach called Secondary Analysis of Qualitative Data (Heaton, 2008). By conducting secondary analysis of an existing dataset of family members bereaved through substance use (Templeton et al. 2016), the team was able to ensure that it avoided ethical pitfalls, for example, asking questions that had already been addressed in other research. Moreover, it facilitated some understanding of the issues FMFCs faced, enabling the researchers to prepare both emotionally and practically for the new data collection. This included an awareness that some FMFCs would have their own current or historical substance problems. This raised the next ethical challenge:

<Z>Ethical challenge 21.4

<B>Question. Family members, friends and carers (FMFC) can also have problems with substance use. How can we capture their experiences of end-of-life care as a FMFC without their substance use stories diverting the focus?

<B>Reflections: Throughout interviews with some FMFCs, they shared their own experiences of being stigmatised due to problematic substance use. They were keen to share their wider experiences of stigma, that is, beyond the end-of-life and substance use services that were the focus of this study. The challenge for the researchers was to ensure research objectives were met in the time available but also avoid ‘closing down’ the voices of FMFCs in a quest to do so. Research time had to be used to meet the aims of the research; collecting data that would not be used is unethical. However, we needed to give the FMFCs space to

voice their experiences of being stigmatised, not only to engage them in the research but also to respect their starting point for their experiences of being a FMFC for someone with problematic substance use receiving end of life care.

Cheryl (62), an ex-partner and friend of someone at the end-of-life, wanted to share her own history of substance use and her response to people who had a problem with it. She described feeling stigmatised by professionals and society throughout her life as a result of problematic substance use from the age of 14 years old. By referring to her own life experiences of feeling 'instantly judged' by health and social care professionals, she explained why she felt angry and 'in conflict' with professionals:

<C>Cheryl 21.1
...the main thing for me, obviously there's nothing that can be done to change what happened, but all I really want is to know, even if just one person feels "I've been listened to" and "when I needed help, it was there, and I wasn't being judged".
<end Cheryl 21.1>

Cheryl felt the interview was an opportunity to share her own life experiences of being stigmatised and the ways in which she had 'shored up' feelings of anger towards professionals in practice who she felt had stigmatised her because of her past substance use. This was reinforced further by the health and social care professionals she came into contact with when she adopted the caring role for her ex-partner at the end of his life.

Ultimately, the researchers had to use their sensitivity and skills to listen and give time to the person's story as well as be tentatively directive in moving the focus towards their

experiences of end-of-life care for their relative and their own needs as a family member, friend or carer. Researchers and professionals should aim to capture the particularities of an individual's situation such as Cheryl's to reflect on the implications for practice. This can feel challenging for the researcher if the respondent is deemed un-obliging in their interview performativity because they may have been under the influence of substances or they may 'hijack' the interview by discussing their own agenda (Alldred and Gillies 2012).

<B>Implications for practice: It is good research and practice to reflect on feelings of discomfort raised by an interview as it enriches knowledge about the nuances of people's experiences of problematic substance use, stigma and end-of-life care. Interactions are sites of performativity where identity (re)construction takes place. It was important that the researcher facilitated FMFCs opportunities to voice their, often unheard, experiences of being stigmatised themselves through their own or their friend / relatives' substance use. Research around end-of-life care and problematic substance use involves capturing information about the private lives of others in a similar way to social and health care practice (Hillman 2017). The stigma associated with problematic substance use is immense and can result in defensiveness. In research and practice, understanding our own attitudes towards substance use and dying, and ensuring we apply our learned principles of anti-discriminatory practice, should be at the heart of an empathic and non-judgemental practice. Giving people the time to tell their story prior to meeting the professional's agenda is far more likely to engage people in conversation and access relevant information than rushing in with a list of questions. Professionals can improve practice by developing an awareness of the ways in which uncomfortable interactions with the FMFCs of those receiving end of life care can enrich their knowledge and enhance their understanding about experiences of stigma and problematic substance use.

<end EC 21.4>

The following ethical considerations stem from the experiences of the professionals who participated in the research.

<Z>Ethical challenge 21.5

<B>Question. How do we work with an individual who continues their problematic substance use in spite of their end of life prognosis?

<B>Reflections: While both the hospice and substance use professionals were non-judgemental of people who chose to continue their use, it nevertheless provided ethical challenges in their day to day work and in their personal and professional responses to people who made that choice. For hospice professionals, there was an acceptance of people's substance use although only alcohol was allowed in the hospices. It was also common practice to offer an alcoholic drink to people on the day unit or ward at meal times. One nursing professional recalled giving an agitated man in the hospice a drink of Bourbon, the brand of which he kept repeating in his limited communication. The professional subsequently struggled with how contrary this course of action was to their training as a medical professional:

<C>Hospice professional 21.1

It's important you know, if he hadn't have been able to say [Bourbon] and he was agitated as hell and everybody is trying to give him some water and some [medication] and actually he's been a drinker all his life, [I said] to his wife, "what is his favourite tipple"? … This sort of thought process and advice goes against everything, when you go and do your nurse training

… if you wrote that in your nursing exam, you'd fail wouldn't you?! Talking about how to address psychological needs and things, “give them some alcohol”, you'd fail wouldn’t you?
<end Hospice professional 21.1>

For some of the substance use professionals, the concern was ‘missing’ offering people the support they needed, or lacking the knowledge of how to do so:

<C>Substance use professional 21.1
…some clients we know will never stop drinking and so it’s actually how we… work with those because if we don’t, it costs a lot of money bouncing back through treatment services, they don't really want to stop drinking, they’re not going to, so I suppose that’s where we’re missing it and those people die at home on their own.
<end substance use professional>

In these examples, both sets of professionals expressed concern about actions they took, or failed to take, that provided ethical challenges. Providing alcohol to someone in distress felt unethical for the hospice professional concerned; failing to provide an adequate, or any service to the person who is drinking and dying in the community was a heavy burden for the substance use professional. Clearly, there are no single solutions. The hospice professional in this example used their initiative and was totally person-centred in doing so. Their creativity and flexibility to step outside their normal practice led to a solution for the person in their care. They were able to affect the support required even though it felt uncomfortable in doing so. For the substance use professional, they were aware of missing people but unclear about how to intervene.

<B>Implications for practice: The fluctuating capacity and needs of people experiencing problematic substance use at the end-of-life requires a flexible and creative approach to practice. Sitting comfortably with professional discomfort may be part of that process providing practice is ethical and value based. Further, the impact on the professionals of these frustrating and challenging situations needs recognition. An important part of supporting people experiencing problematic substance use at the end-of-life is self-care of the professional. Being emotionally and psychologically able to do the work needs considered attention. Thus, making good use of internal or external supervision to process the frustrations, emotions and sadness of some situations is equally as important as the knowledge or training on the topic. Supporting someone through a process of self-harm using substances is difficult when it is exacerbating their condition and hastening their end. Further, reflecting on how the behaviour supports or challenges our values is vital in order to prepare adequately for practice and to understand that we may have to work and live with some element of discomfort if care is to be as person-centred and needs led as possible.
<end EC 21.5>

<Z>Ethical challenge 21.6
<B>Question. How do we manage pain medication for people with current or previous histories of problematic substance use?

<B>Reflections: Concerns about under- or over-prescribing pain medication was probably the key concern raised by professionals in the hospice settings. For people with current or previous opiate use, the professionals spoke of difficulties in knowing how much opiate based painkillers to prescribe and whether the prescribed amount would be sufficient or too much. The risk of under prescribing was leaving someone in pain potentially; prescribing too

much risked overdosing them. The practice of medicating strong opioids for pain relief (NICE 2012b) must consider the individual's levels of tolerance to painkillers and the interaction with other prescribed or illicit medication or drugs.

<C>Hospice professional 21.2

Poly-prescribing is a big issue, poly-pharmacy is a big issue so when you've got lots of different people prescribing, you can't keep track of what they're getting and when they get it, or from whom.

<end hospice professional 21.2>

<C>Hospice professional 21.3>

And people start taking … cumin, turmeric and mushrooms and cannabis oil, a lot of these things… but it made it very difficult because we're prescribing drugs that we know interact to a degree that you can't predict because there's no trials but they know from the pharmacy that there's an interaction, and I think more and more, there are people taking particularly cannabis in various forms, oils, smoke, whatever it is and it's those unknown interactions that also add a new layer of complexity that you don't really know what these herbal homeopathic remedies are doing.

<end hospital professional 21.3>

<B>Implications for practice: The challenges for prescribing practice do not have easy solutions. The variations in who has taken what and its impact on prescribed medication interactions will be many and varied. Getting a more honest and open answer about other

substances used is, however, far more likely when the professional has proven their trust in their approach, genuine manner and care for the person concerned. If the person feels judged by the tone or manner of the questions then, understandably, they are more likely to be deceptive. If their honesty is met with condemnation and criticism, why would they be honest? Setting out the professional's concerns in a non-judgemental manner and encouraging a dialogue rather than a one-way lecture about drug interactions is more likely to achieve the desired result. The use of various substances can then remain a topic for reconsideration each time medication, treatment and wider care is reviewed.

<end EC 21.6>

<Z>Key Points 21.1

<bullet>

- Listening to people's experiences of services is an important part of research and practice. It is crucial to ensure that something is done with the information gathered. Operational change can take place at individual and organisational levels and professionals need to be clear on their agency and remit to act on information supplied.
- Having conversations with people about their health, substance use, death and dying are important components of providing effective health and social care, including appropriate medical treatment and social support.
- Flexibility with 'normal' procedures of assessment and the time taken to collect information may be required. Professionals working alongside people with current problematic substance use and end-of-life care needs must be prepared to respond with patience to a person's fluctuating capacity.

- Being honest about our attitudes towards problematic substance use, and our personal and professional experiences of it, will help to ready professionals for meeting it in practice and responding appropriately.
- Sitting comfortably with discomfort is likely to be part of the role of health and social care professionals working alongside people who are at the end of their lives who choose to continue to use substances. Seeking support appropriately is an important part of professional self-care.

<end bullet>

<end KP 21.1>

<Z>Self-Assessment Exercises 21.1 – Opening a box full of emotions

<B>Time: 30 minutes

Drawing on what you have read here, identify a situation or interaction where you avoided discussing your feelings and emotions.

<bullet>

- What was the situation and why did you avoid discussing your feelings?
- What strategies did you use to avoid talking about feelings and emotions?
- In what ways, did your avoidance behaviour impact on the interaction and those involved in it?

<end bullet>

<end SAE 21.1>

It is not uncommon for people to avoid talking about emotions. Talking about our emotions can make us feel exposed. For people experiencing problematic substance use who are receiving end-of-life care, talking about their emotions can add to their feelings of

vulnerability. These feelings may include fear, frustration, distress, shame and denial. Past unhelpful experiences of interactions with health and social care professionals can compound a person's unwillingness to openly discuss their feelings for fear of further stigmatisation whilst needing end-of-life care. Our role as current or aspiring professionals is to use skills, experience and knowledge to support a person at end-of-life in ways which minimise any distress or difficulties they may be experiencing whatever their choice of lifestyle.

<Z>Self-Assessment Exercise 21.1 - Talking to people about substance use at the end of their lives

<B>Time: 20 minutes

Talking to a person about their substance use initially does not require an assessment tool or set of questions. First and foremost, it is a conversation with compassion.

<bullet>

- Devise two questions about substance use and two questions about death and dying that would help begin a conversation and be appropriate for your practice context.

<end bullet>

<end SAE 21.1>

The questions of what substances people are using, when, how and why, do not need asking at this early stage. The questions can be open and broad, for example, "How does your drinking/drug use help you"? "Would you like to change your drinking/drug use in any way"? Your tone of voice and the way the questions are asked are hugely important. Further resources to help conversations about substance use can be found below.

Questions about death and dying also need to be approached with warmth and care, for example, “Have you ever thought about the end of your life and how you would like that to be?” or “I understand that you would like to continue drinking (or using substances). Can we have a conversation about the implications of that for your care and treatment from this point on so we can meet your needs?”

Asking people about their substance use or serious health conditions can be uncomfortable for professionals if they do not feel knowledgeable or confident enough. The key to asking people about their substance use is to remember they, not us, are the expert. We are there to learn from them.

<A>Conclusion

This chapter has identified ethical challenges in research and practice with people whose use of substances is problematic and who are receiving end-of-life care. It illustrates how this combination of conditions can challenge received practice and research wisdom. Many health and social care professionals are well equipped to respond to complexity within set structures and systems. We argue that overcoming this particular set of challenges requires a commitment to a truly needs-led and person-centred approach that may involve breaking with traditional ways of working. Further, it requires the professional to reflect on their knowledge and skills base and to seek support to improve in any areas as needed. People experiencing substance problems are often marginalised and stigmatised within service provision. The voices of the people who took part in the study reflect this sense of exclusion. As this chapter has illustrated, their needs are often not heard, or they are overlooked by professionals who perceive them as somehow undeserving. While their use of substances can present psychological, behavioural, and physiological challenges to those who seek to support them,

people do not start out using substances with the intention of developing a problem or being viewed as untrustworthy, troublesome, and unreliable. As separate issues, both substance use and end-of-life care pose professional and personal challenges. Combined, these challenges are magnified, but people experiencing substance problems, at the end of their lives, still deserve choice, respect, care and compassion, regardless of their lifestyle choices.

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<W>To Learn More

This is a new area of research and practice development and therefore current resources are scarce. There is some literature focussing on aspects of care, for example, on pain management for people with histories of substance use, or on particular groups of people with co-existing substance use and end of life care needs, for example, homeless people. We have included a sample of this literature below. Until more targeted resources are available[3], we have also provided a number of resource links to broadly relevant areas including research reports, websites and journal articles.

<A>Articles

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[3] Contact the authors for resources currently in progress.

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<A>Reports and guidance

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British Association of Social Workers series of pocket guides for working with alcohol and other drugs (2012): www.basw.co.uk/pocket-guides/

Homelessness and end of life care report and information pack. www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/current-partnerships/homeless_report.pdf

Care Quality Commission (2016) *A different ending. Addressing inequalities in end of life care. Good practice case studies.* www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review

<A>Websites

Alcohol Concern – national alcohol charity in England and Wales www.alcoholconcern.org.uk

BEAD Project (Bereaved through alcohol or drugs) - www.beadproject.org.uk/

Marie Curie – webpage on addiction at end of life for healthcare professionals www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/symptom-control/addiction-at-end-of-life

Working with substance use – Open Educational Resource from Health Education North West - https://workingwithsubstanceuse.wordpress.com